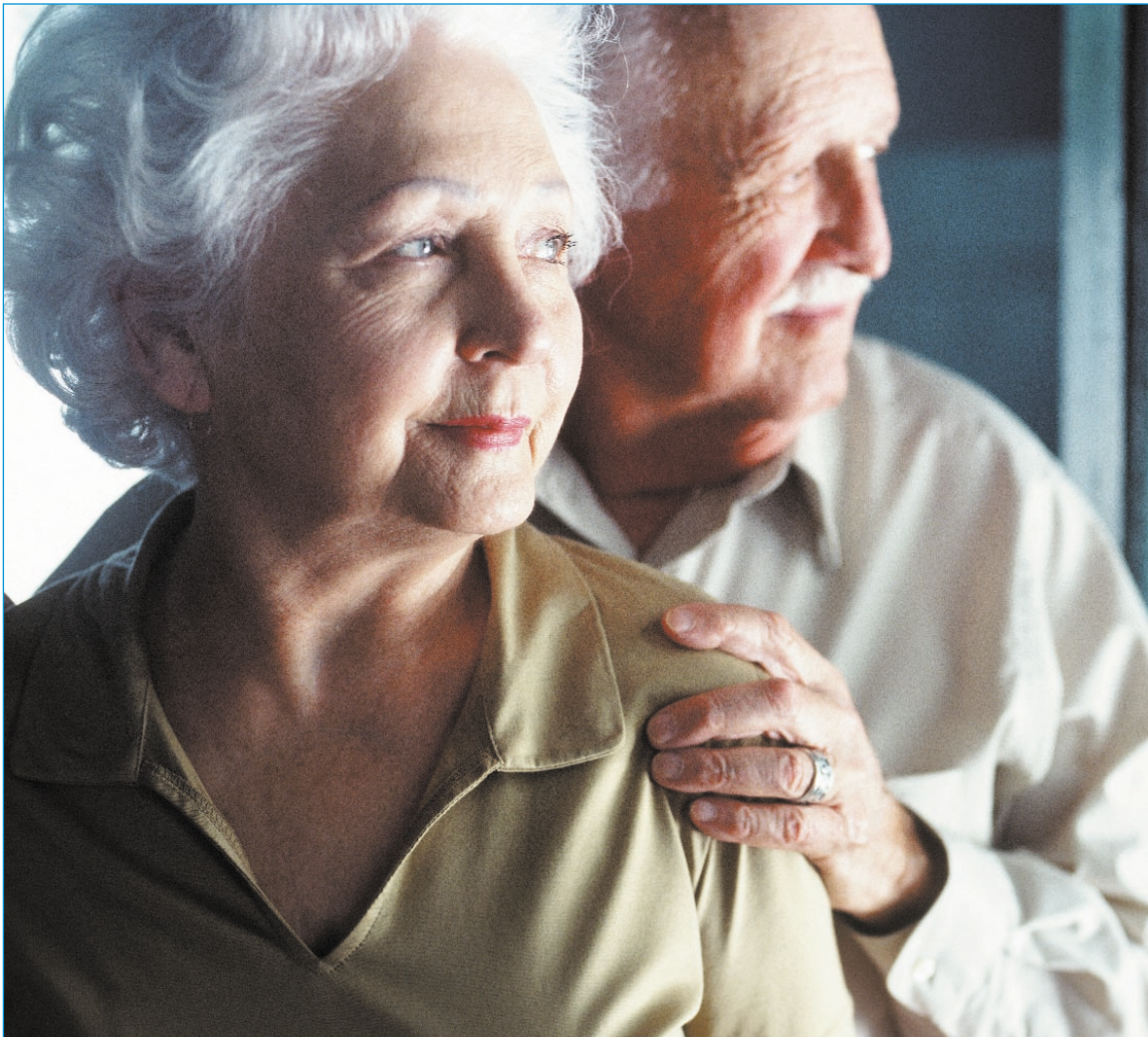


Family Caregiving In Utah



*A Guide
for Family Caregivers*



Are you a caregiver?

If you provide any of the following for another person you are probably a caregiver:

- **Help with paying bills**
- **Help with household chores such as shopping, cooking, laundry, and/or home maintenance**
- **Help with personal care (dressing, bathing, feeding, toileting)**
- **Help moving around the house**
- **Help with transportation**
- **Help with taking medications**
- **Companionship by personal visits or telephone**
- **Help with making or receiving telephone calls**
- **Help arranging/coordinating outside services**

If you said yes to any of these questions you are probably a caregiver, and you're not alone. Nationwide one of every four persons is providing care for a relative or friend, age 50 or older. You're part of a very important and diverse group. Caregivers can live with their relative or provide long-distance caregiving. Some family caregivers are employed and might also be juggling the care of a parent and children. Caregiving demands time, resources, love, and energy. While there is currently no one-stop shop to get all of your questions answered, there are resources and people who can help. Your local Area Agency on Aging (AAA) is an important place to begin.

Utah's network of caregiving service providers have designed this booklet to help you navigate the caregiving maze by:

- Providing information about basic caregiving resources
- Identifying your local resource team
- Helping you develop a care plan

Utah Caregiver Support History

Caregiver Initiatives

While Utah has offered services to caregivers for a number of years, nationally there was no comprehensive program to assist family caregivers. However, in 2000 the National Family Caregiver Support Act helped fill this gap. This act authorized a variety of services to support the important work of family caregivers.

Through this federal legislation, Utah has started a new effort to assist family members and friends in their caregiving roles. The Utah Caregiver Support Program strives to complete the care by making

information, supports and services available to help caregivers. Utah's Caregiver Support Program is administered by the Department of Human Services, Division of Aging and Adult Services, with direct services provided through the Area Agencies on Aging (AAA) and local contractors.

Through the Utah Caregiver Support Program, public and private organizations statewide are partnering to provide information and services to family caregivers and to educate and train the professionals who work with them. These groups have formed local partnerships that make up the Utah Coalition for Caregiver Support.

A 2002 survey showed that 172,955 Utah households provide care for a family member or friend age 50 or older.

Eighty percent of care provided to older adults is done informally by family and friends. The value of this care to the Utah economy is estimated to be \$1.3 billion annually, nationally that figure would be \$45 to 98 billion.





The Utah Coalition for Caregiver Support Mission

- 1 To enable individuals to recognize their roles as caregivers.
- 2 To promote awareness about the issues, challenges and rewards of caregiving for older adults.
- 3 To coordinate a network of support for caregivers and providers and to help remove barriers to resources.

Area Agencies on Aging (AAAs)

AAAs provide a link to in-home services, or services that provide temporary relief for persons caring for an individual who is ill, injured or frail (also known as respite services). These services can be provided at home, in an adult day care center or other setting.

Other services include:

- home-delivered meals
- congregate meals
- adult day programs
- care management
- in-home aide service
- information and assistance
- senior center programs
- transportation
- health promotion
- housing and home-improvement
- medication management
- abuse, neglect or exploitation education and awareness

The availability of these services varies in each county. Contact the Utah Caregiver Support

Program at your Area Agency on Aging, or visit the Division of Aging and Adult Services' online directory of local services.

Support Groups

Support groups can be found across the state. Many are designed for caregivers of people with specific diseases and are often sponsored by national associations like the Alzheimer's Association and the American Parkinson Disease Association. (See Resources page for more information.)

There are also general caregiver support groups. Many groups are sponsored by local aging service providers or faith-based organizations. A growing number of support groups are offered online as an option for caregivers who have Internet access but limited time or ability to attend group meetings.

Support groups allow caregivers to:

- discuss their concerns and frustrations
- receive and offer emotional encouragement
- share practical solutions to caregiving situations

Training / Workshops

A variety of workshops and training resources are available to assist caregivers in carrying out their role. The workshops may include:

- Taking medication
- Getting information and access to available resources
- Caregiver self-care techniques
- Home safety
- Dealing with difficult behaviors
- Transfer techniques

For information, contact your local Area Agency on Aging, the Utah Caregiver Support Program at (801) 538-3910 or visit the Utah Caregiver Support Calendar of Events at www.caregivers.utah.gov.

USE THE FOLLOWING CHART TO HELP DEVELOP A CAREGIVING PLAN:

My relative	What they need	Where can they get it
...really needs to get out and socialize	Socialization / Volunteering – Programs	Senior centers, adult day care, friendly visitors, city recreation department, Faith in Action, the Utah Commission on Volunteers.
...is grieving over the death of a loved one	Bereavement Support – Dealing with the normal grieving process.	Bereavement support programs, hospice programs, hospitals, local funeral homes.
...cannot drive or use public transportation and taxicabs are too expensive	Transportation for older persons	AAAs, private transportation, people with disabilities transportation.
...is unable to remain in his / her present housing	Special housing options are available for the elderly	Local housing authority, local AAAs, geriatric care managers.
...needs help with food preparation and/or housekeeping and/or laundry	Homemaker Services – Non-medical service to help an older person remain in the home.	Private homemakers, personal care agencies, local AAAs.
...needs help with personal care (bathing, dressing, grooming, toileting)	Home Health or Personal Care Aide – Personal and basic health care provided by a specialist.	Home health agencies, public health nurses, personal care agencies, geriatric care managers.
...needs skilled nursing, occupational, speech or physical therapy	Skilled nurse or therapist	Home health agencies, public health nurses, geriatric care managers.
...really needs 24-hour supervision even though he/she fights it	Private Home Care, Nursing Home Care– 24-hour medical supervision.	Personal care agencies, home health agencies, local AAAs, geriatric care managers.
...cannot be left alone during the day	Monitoring/Safety-Volunteers who visit with the elderly or a facility which provides constant supervision	Adult day care, live-in attendant, local AAAs, home health agencies, geriatric care managers.
...has health care costs which are overwhelming	Reducing cost of quality health care.	Medicare, Medicaid, local AAAs.
...is depressed / suspicious / angry all the time, just sits	Talk with primary care physician. A mental health evaluation may be necessary to assess psychological stability.	Mental Health Departments, geriatric care managers, psychiatric hospitals, emergency room.
...has a terminal illness and wants to die at home	Hospice – Medical and social services designed for terminally ill patients.	Utah Hospice Organization, Cancer Society, church or synagogue



Financial / Legal Resources

Legal Services

Many older people experience problems that threaten their autonomy, dignity, health, income, rights, and security. Many of these problems can be avoided or remedied by legal intervention. See resource information, page 7.

Advance Directives

Advance care planning is deciding about the kind of health care you want at the end of life. Advance health care directives are the legal documents that you share with your health care providers and appropriate family members to make sure you get the kind of treatment you want if you can't speak for yourself.

End-of-Life Care Partnership of Utah provides a step-by-step guide to advance care planning. The workbook, Tool Kit for Health Care Advance Planning, is designed to help individuals and families plan for the care they want at the end of life.

Health Insurance Information

Medicare:

Most adults, age 65 and older and certain disabled adults receive Medicare health insurance. Medicare only covers a portion of costs such as hospitalizations, doctors' visits, and diagnostic testing. In some cases, it may cover short-term care in a skilled nursing facility and limited home health care. Medicare-approved home health care may include the services of a nurse, physical therapist, speech therapist, medical social worker, occupational therapist and home health aide. Medicare is the national health insurance program for people age 65 and older and for some younger persons with disabilities.

It is divided into two parts: Hospital Insurance (Part A) and Medical Insurance (Part B).

Medicare, Part A

helps pay for care in a hospital or nursing home, limited home health services, and hospice care. There are usually no premiums to pay for Medicare Part A, but there is an annual deductible and a coinsurance payment.

Medicare, Part B

helps pay for doctors' services, outpatient hospital care, and other medical services that Part A doesn't cover.

Many people still think that Medicare provides

According to AARP, 20-30% of all adults are estimated to have advance directives, yet in nearly 35% of those cases, the directives cannot be found when needed.

long-term care. The reality is that there is no long-term non-medical care coverage under Medicare. Medicare does provide limited short-term care after a hospital stay, and home health care services only under certain conditions. Coverage is not available for long-term chronic care. Medicare does provide a hospice benefit for persons with a terminal diagnosis. The benefit covers all non-curative services and medications administered under hospice.

Medicare also provides a hospice benefit for persons with limited life expectancy. Hospice covers medications related to the life-limiting diagnosis, nursing, home health aides, medical equipment, social work, and chaplain services. For more information on Medicare coverage and benefits, call your local AAA, or visit www.medicare.gov.

Medicaid:

A program that provides health care insurance for low-income older and disabled adults. It also covers nursing home care for eligible individuals. Contact your Department of Work Force Services for eligibility information. For information call 800-662-9651.

Private Insurance:

Since Medicare does not cover all health care costs, most Medicare beneficiaries have additional private coverage either through their former employers or with a Medicare Supplement policy. Additional long-term care insurance can be purchased to cover some of the costs of home care and nursing facility care. There are limits on both of these types of insurance as well as state laws to protect the consumer. For insurance counseling and assistance, call the Health Insurance Information Program (see Contact Information) or the Department of Insurance at www.insurance.utah.gov.

Federal Tax Benefits

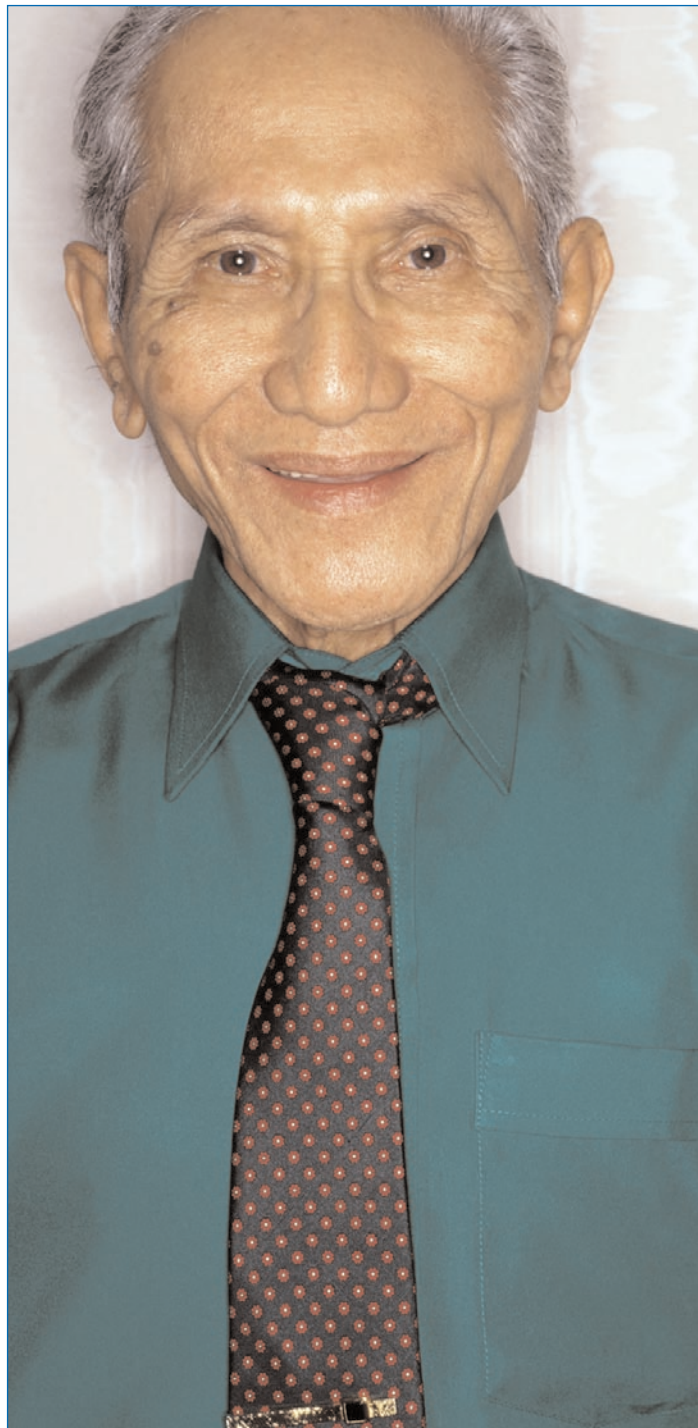
You may be able to claim a tax credit if you pay someone to care for your spouse or dependent who is not able to care for him/herself. The credit can be up to 30% of your expenses. For further information, contact the Internal Revenue Service online at www.irs.gov.

Assistance in Filing Tax Benefits

AARP-Tax-Aide and Volunteer Income Tax Assistance (VITA) programs offer free assistance in preparing tax returns. For information contact AARP Tax-Aide at 888-227-7669, or see the website: www.aarp.org/taxaide. For VITA call (800) 829-1040 or see the website: www.irs.gov.

Family and Medical Leave

Under the Family and Medical Leave Act (FMLA) of 1993, employees meeting eligibility requirements can take up to 12 weeks of unpaid, job-protected leave in a 12-month period to care for an ill family member. Check with your employer for eligibility questions, or visit the website www.dol.gov/elaws/fmla.htm.



RESOURCE INFORMATION

AARP Utah, 866-991-2277 or 801-561-1037

A membership organization for people 50 and over that provides information, education and advocacy on legislative, consumer and legal issues.

Visit: www.aarp.org/life

Adult Protective Services, 800-371-7897

Investigators are located throughout the state and work with agencies and family members to stop abuse, neglect and exploitation of older adults. Any person who has reason to suspect such abuse is mandated by law to report their concerns.

Alzheimer's Association, Utah Chapter, 800-371-6694 or 801-265-1944

Provides education and support for people diagnosed with Alzheimer's disease and other dementia, and to their families and caregivers.

Visit: www.alzutah.org

American Cancer Society, 800-234-0533, 801-483-1500

Dedicated to eliminating and preventing cancer through research, education, advocacy and service.

Visit: www.cancer.org

American Parkinson Disease Association, 801-585-2354

Provides education and support for people with Parkinson's disease.

Visit: www.apdaparkinson.com

The Arc of Utah, 800-371-5060, 801-364-5060

Advocates for and supports persons with developmental disabilities.

Visit: www.arcutah.org

Benefits Checkup, 866-991-2277

Service of the National Council on Aging that provides specific information to individuals about benefits they might be eligible for, as well as resources for the cost of prescription drugs.

Visit: www.benefitscheckup.org

Easter Seal Society, 801-486-3778

Provides services to help children and adults with disabilities and/or special needs as well as support for their families.

Eldercare Locator, 800-677-1116

Helps older adults and their caregivers identify local support resources.

Visit: www.eldercare.gov

End-of-Life Care Partnership, 888-918-4490

Provides education and resources on preparation for end of life.

Visit: www.carefordying.org

Health Insurance Information Program (HIIP), 800-541-7735

Provides assistance with questions on health insurance; Medicare, Medigap, long-term care insurance.

Visit: www.hsdaas.utah.gov/hip_contact_list.html

Information and Referral Center, 211 or 800-472-4716

Provides human service resource information and referral over the telephone, much like 411.

Visit: www.informationandreferral.org

Lawyer Referral Service of the Utah State Bar, 801-531-9077 or 1-800-698-9077

Provides names of private lawyers who handle cases for a fee.

Visit: www.utahbar.org

Nursing Home Quality Initiative, 866-708-1944, ext.625

Provides detailed information on past performance of every Medicare and Medicaid certified nursing home in the state.

Visit: www.medicare.gov/NHCompare/home.asp

Social Security Administration, 800-772-1213

Handles applications for retirement, disability, survivor's Medicare and Supplemental Security Income (SSI)

Visit: www.socialsecurity.gov

Utah Legal Services, Inc. 801-328-889, 800-662-4245

Free legal services for low-income persons and those 60 years of age and older.

Visit: www.uls.state.ut.us

Utah State Division of Aging and Adult Services, 801-538-3910

Provides leadership and advocacy in addressing issues that impact older Utahns.

Visit: www.hsdaas.utah.gov

GLOSSARY

Activities of Daily Living (ADL) - routine activities that we all do on a daily basis – bathe, dress, eat, go to the bathroom, move around the house.

Instrumental Activities of Daily Living (IADL) – common activities that require higher physical and mental skills– housework, preparing meals, managing our finances, getting to appointments, taking medications, etc.

Advanced Directives (Advance Care Planning) - documents that outline your wishes regarding healthcare at the end of life or in the event of a catastrophic illness. In Utah, these documents can include a Living Will, Medical Treatment Plan and Healthcare Power of Attorney.

Assisted Living Facilities - facilities that provide assistance with ADLs and IADLs, but do not provide 24-hour skilled nursing care. Housing for those who may need help living independently but do not need skilled nursing care. The level of assistance varies among facilities and may include help with bathing, dressing, meals, and housekeeping.

Case Management - a service offered by many organizations to help coordinate community services for persons living at home, in assisted living facilities or in a nursing home.

Co-payment - a shared cost that a person must pay when accessing their health benefit plan (health insurance.)

Durable Power of Attorney for Finances - a legal document that establishes who will have legal authority to make financial/legal decisions on your behalf, and remains effective if you become incapacitated.

Family Caregiver - an adult family member, or another individual, who provides informal in-home and community care to an older individual.

Geriatrician - a medical doctor who specializes in the treatment of older people.

Home Health Care - care that is received in the home or assisted living setting . It may be paid for by Medicare, insurance, or private funds.

Hospice - specialized care and support for terminally ill persons and their families.

Long-term Care - refers to a broad range of services needed by persons with physical or mental impairments who do not have the ability to function independently. Care can be provided in the home, community, assisted living facility or institutional setting (hospital or nursing home).

Personal Care - assistance with bathing, dressing, toileting.

Support Group - formal or informal groups that meet to discuss issues of common interest/concern, such as caring for a person with Alzheimer's disease, stroke or diabetes.



AREA AGENCIES ON AGING, BY COUNTY

Bear River AAA (BRAG)

170 N. Main
Logan, UT 84321
(435) 752-7242
(Box Elder, Cache and
Rich Counties.)

Davis County Council on Aging

50 E. State Street
Farmington, UT 84025
(801) 451-3370

Five County AAA

1070 West 1600 South,
Bldg. B
St. George, UT 84770
(435) 673-3548 or
(435) 586-2975
(Beaver, Garfield, Iron,
Kane and Washington
Counties)

Mountainland AAA

586 East 800 North
Orem, UT 84097
(801) 229-3800
(Summit, Wasatch
and Utah Counties)

Salt Lake County Aging Services

2001 S. State Street
Salt Lake City, UT 84190
(801) 468-2480

San Juan County AAA

117 S. Main Street
Monticello, UT 84535
(435) 587-3225

Six County AAA

250 N. Main Street, #5
Richfield, UT 84701
(435) 896-9222
(Wayne, Piute, Juab,
Sanpete, Millard,
and Sevier Counties)

Southeastern Utah AAA

375 S. Carbon Avenue
Price, UT 84501
(435) 637-4268
(Carbon, Emery and
Grand Counties)

Tooele AAA

59 E. Vine Street
Tooele, UT 84074
(435) 882-2870

Uintah Basin AAA

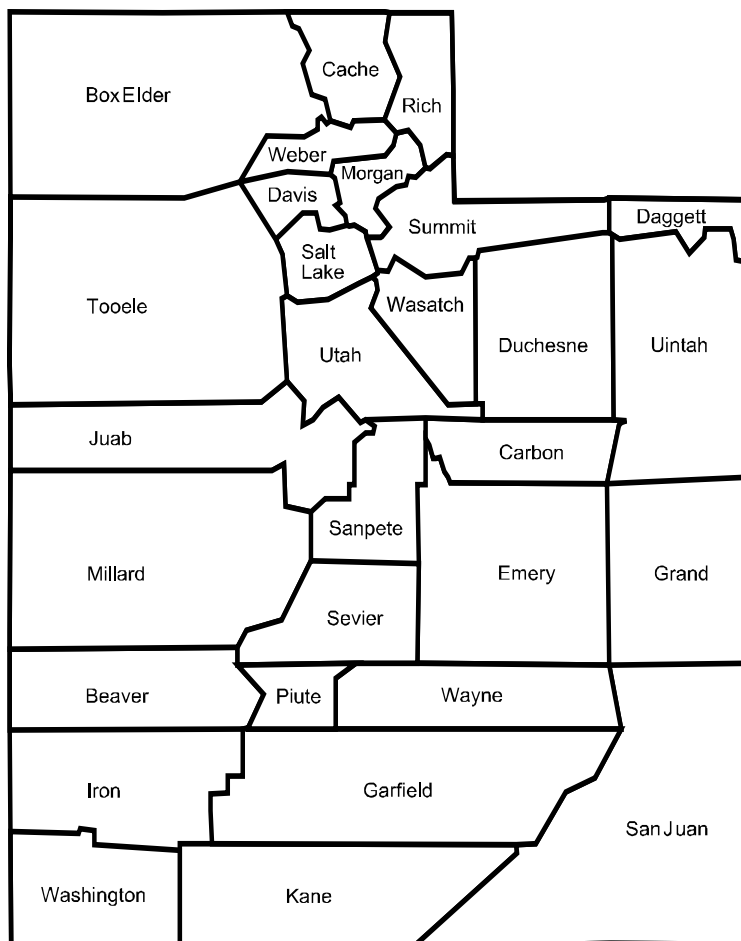
255 East 200 North,
#112
Roosevelt, UT 84066
(435) 722-4518
(Daggett and
Duchesne Counties)

Uintah County AAA

155 South 100 West
Vernal, UT 84078
(435) 789-2169
(Uintah County)

Weber-Morgan AAA

237 26th Street
Ogden, UT 84401
(801) 625-3770
(Weber and Morgan
Counties)



NOTES

Begun in March 2002, the Utah Coalition for Caregiver Support has grown to include 32 member organizations from around the state. With regular monthly meetings, this diverse group came together on the issue they all share — caregiving.

This publication is a result of the collaboration of Coalition members, the Utah Caregiver Support Program of the Division of Aging and Adult Services, AARP Utah and coalition member organizations:

American Association of University Women
Alzheimer's Association
CHRISTUS St. Joseph Villa
Church of Jesus Christ of Latter Day Saints
Golden Years Consultants
Goodwill Initiatives on Aging/ Neighbors Helping Neighbors
Governor's Initiative on Families Today
IHC Employee Assistance Program
Jewish Family Services
KUED Channel 7
Legislative Coalition for Persons with Disabilities
Society for Human Resources Management
Sunshine Terrace Foundation
University of Utah Gerontology Center
University of Utah College of Nursing
Utah Association for Home Care
Utah Association of Area Agencies on Aging
Utah Hospice Organization
Utah Home Care Association
Valley Mental Health, Masters Program

